Healthcare Transition for Youth Living With HIV: Outcomes from a Prospective Multi-site Study

By: Amanda E. Tanner, Morgan M. Philbin, Brittany D. Chambers, Alice Ma, Sophia Hussen, Samuella Ware, Sonia Lee, and J. Dennis Fortenberry

AE Tanner, MM Philbin, BD Chambers, A Ma, S Hussen, S Ware, S Lee, JD Fortenberry. (2018). *Journal of Adolescent Health* 63 (2) 157-165.

Made available courtesy of Elsevier: https://doi.org/10.1016/j.jadohealth.2018.02.004

Abstract:

Purpose: Youth living with HIV (YLHIV) in the United States (U.S.) account for nearly one-third of new HIV infections and face significant barriers to care engagement; only 25% are virally suppressed. Healthcare transition (HCT) from pediatric/adolescent to adult-oriented care can be particularly disruptive. Accordingly, we prospectively examined HCT processes at 14 distinct geographical sites across the U.S.

Methods: We collected Audio Computer-Assisted Self-Interviews data and abstracted electronic medical records from 135 HCT-eligible YLHIV at baseline and 9-month follow-up. Descriptive analyses and multilevel modeling were conducted. Data also included qualitative interviews with 28 adolescent and 30 adult providers across 14 adolescent and 20 adult clinics, respectively. Interviews were analyzed using the constant comparative method; this analysis focused on specific HCT recommendations.

Results: At baseline, youth were primarily age 24 (78.8%), male (76.8%), black (78.0%), identified as a sexual minority (62.9%), had attended an HIV appointment in the past 3 months (90.2%), had Medicaid for insurance (65.2%), and were always or mostly always adherent to their antiretroviral therapy (65.9%). At the 9-month follow-up only 37% of YLHIV successfully transitioned to adult care. Both individual-level (insurance status and disclosure-related stigma) and clinic-level (adolescent clinic best practices) factors were significant. Adolescent and adult clinic staff offered recommendations to support HCT; these focused primarily on clinical changes.

Conclusions: This study highlights the complex set of individual- and clinic-level factors associated with HCT. Addressing these key factors is essential for developing streamlined, comprehensive, and context-specific HCT protocols to support continuous care engagement for YLHIV.

Keywords: Healthcare transition | Adolescents | HIV | Clinical Care

Article:

Implications and Contribution

Youth living with HIV face significant barriers to care engagement across the HIV care continuum. Healthcare transition from pediatric/adolescent to adult-oriented care settings can be especially disruptive. Addressing individual- and clinic-level factors is essential to support continuous care engagement during healthcare transition and fully realize the benefits of biomedical innovations.

Pediatric/adolescent and adult-oriented clinical settings have different medical subcultures and approaches, particularly for youth with chronic diseases [1]. These differences include provider training (e.g., approach to adolescent developmental issues), design of clinical space (e.g., "youth friendliness"), and support services (e.g., pediatric/adolescent clinics are more likely to have onsite mental health specialists and to provide housing or education-related support) [1], [2], [3]. Pediatric/adolescent and adult clinics often have different behavioral expectations for their patients: pediatricians and adolescent medicine physicians are trained to ensure that youth reach developmentally appropriate milestones [1] whereas adult clinics expect that youth comport themselves as adults and accept associated responsibilities (e.g., on-time appointment arrival) [4]. Further, adult providers are trained to focus primarily on disease management as opposed to providing ancillary services and development-specific support [3]. These clinical and disciplinary differences have distinct and direct implications for the treatment of youth with chronic diseases, particularly during healthcare transition (HCT) from pediatric/adolescent to adult care.

Because of medical advances, youth living with chronic diseases [5], such as diabetes [6], cancer [7], and HIV [8], have the ability to lead long, healthy lives. However, to fully benefit from these medical advances, youth must successfully transition to adult care, a process that requires coordination from both pediatric/adolescent and adult providers. HCT is particularly challenging for youth living with HIV (YLHIV) given that, as an infectious disease, HIV requires both behavioral and clinical care management. HIV care engagement and continuity is critical for YLHIV to remain adherent to medication, obtain and maintain viral suppression, reduce transmission, and limit morbidity post-HCT [9], [10], [11], [12]. Extant research highlights barriers to care linkage and engagement (e.g., developmental capacity, insurance, and transportation) of YLHIV [13], but barriers to HIV-related HCT are less well documented [14]. YLHIV typically transition to adult care in their early 20s [15], [16]—usually by age 24—and approximately 25,000 YLHIV will reach transition age by 2025 [17]. A better understanding of factors that affect "transfer" (the actual movement of care from pediatric/adolescent to adult care systems) [16] and "healthcare transition" (the purposeful movement of youth from child-centered to adult-centered care) [1] is therefore crucial. Retrospective single-center studies indicate that only 50% of youth remain engaged in care 1-year post-HCT [18], [19], but there is a lack of prospective, longitudinal HIV-related HCT data, particularly across multiple sites [16], challenging our ability to support YLHIV during HCT. This study aimed to address this gap by prospectively examining individual- and clinic-level factors associated with HCT to adult care in

YLHIV. The study incorporates mixed method data from YLHIV as well as adolescent and adult clinic providers, all key players in HCT success, to provide a comprehensive and nuanced description of experiences with transition of YLHIV.

Methods

Study overview

Data for the mixed method Comprehensive Assessment of Transition and Coordination for HIV-infected Youth as they Move from Adolescent to Adult Care (CATCH) study were collected from YLHIV and pediatric/adolescent and adult clinic providers across 14 Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) sites across the United States (U.S.) [4], [14]. Participants received a $25 gift card. Institutional review boards at the University of North Carolina Greensboro and participating ATN sites approved study protocols.

Youth data

YLHIV were eligible if they were behaviorally infected, preparing to transition to adult HIV care within 6 months (as reported by their healthcare provider), spoke English or Spanish, and received care at an ATN clinic. Youth provided informed consent and signed a bidirectional release of electronic health record information. Study staff recruited 156 adolescents; 21 declined to participate. Audio Computer-Assisted Self-Interviews (ACASI) data were collected at the adolescent clinic from the 135 YLHIV at baseline (August 2015–February 2016) and at 9-month follow-up (May–November 2016). Electronic health record data were abstracted to confirm whether a youth had successful HCT (defined as at least one adult clinic appointment during the study period) and viral load (from the laboratory results closest to the ACASI data collection). YLHIV data in these models were collected at baseline to predict HCT at follow-up.

Individual-level HCT-related variables [16] included demographic, psychosocial, care engagement, and adolescent clinic services. Demographic variables included being 24 years old (typical HCT age at these clinics [20]) versus younger, current male gender versus nonmale gender (i.e., female or transgender woman), Hispanic versus non-Hispanic, and no insurance versus insurance. Adherence to antiretroviral therapy was dichotomized as always or mostly always (≥95%) adherent versus less consistent adherence using a validated self-report measure [21]. Psychosocial variables included the two-item disclosure-related stigma scale (Likert scale: 1/strongly disagree to 4/strongly agree): “I am very careful who I tell that I have HIV,” and “I worry that people who know I have HIV will tell others.” Higher summed scores indicated higher levels of perceived stigma. Psychological distress was measured by the Brief Symptoms Inventory Scale. Raw scores were summed across 18 items related to feelings of depression (e.g., feeling blue), somatization (e.g., faintness or dizziness), and anxiety (e.g., feeling hopeless about the future) in the past 7 days, then converted to T-scores ($M = 50$, $SD = 10$). T-scores greater than 64 denoted psychological distress. YLHIV care engagement was defined as HIV appointment attendance in the past 3 months. Services YLHIV received in the adolescent clinic were dichotomous (yes/no) and included whether staff discussed potential transition challenges, provided support in choosing adult clinic, and discussed differences between adolescent and adult health systems.

Clinic-level data

Researchers conducted 58 semi-structured telephone interviews from August 2015 to June 2016 with adolescent clinic (n = 30) and adult clinic (n = 28) medical and social service providers directly engaged with HCT. Interviews occurred across 14 adolescent and 20 adult clinics, averaged 45 minutes in length (range = 22–78 minutes), and were professionally transcribed. The interview guide addressed processes, factors, and recommendations specific to HIV-related HCT [4].

Data also include a clinic checklist (adapted from the National Diabetes Education Program Transition Planning Checklist [22] and American Academy of Pediatrics [23] HIV Transition Recommendations) to capture clinic specific HCT-related strategies (e.g., life skills training and adolescent clinic staff attending the first adult clinic appointment of YLHIV), logistical characteristics (e.g., adolescent and adult clinic/provider associated with the same institution), and comprehensive patient services (e.g., mental health services, support groups, and/or reproductive health services).

Two HCT "Best Practices" scales were created from checklist data. The first, adolescent clinic best practices, included eight items from 13 adolescent clinics (one clinic was excluded as it did not transition any YLHIV during the study). Items were scored as yes/no and included (1) having a HCT protocol; (2) having a specific "transition" staff person; (3) having an adult provider come to the adolescent clinic to treat/meet youth before HCT; (4) having an adolescent clinic staff attend a youth's first adult clinic appointment; (5) providing information and support to youth regarding adult clinic options; (6) providing youth with information about insurance protocols (e.g., making insurance claims); (7) having one adult clinic versus multiple adult clinics available for HCT; and (8) whether the receiving adult clinic was within the same clinical space/medical system or a different medical system. Responses were summed and scores ranged from 0 to 8; the scale was dichotomized to compare adolescent clinics that practiced seven or eight best practice strategies versus adolescent clinics that practiced six or fewer strategies. Similarly, the adult clinic best practices scale included four items and asked whether an adult clinic had (1) a clinic HCT protocol; (2) a specific HCT staff person; (3) an adult provider who goes to the adolescent clinic to treat or meet youth prior to transition; and (4) an adolescent clinic staff who attends the first adult clinic appointment with youth. Responses were sum scored and dichotomized to compare adult clinics that practiced all four strategies compared with three or fewer.

Quantitative analyses

Descriptive statistics assessed youth and clinical characteristics. Youth were nested within specific clinics necessitating a multilevel modeling approach; mixed effects logistic regression was used to test associations between clinical practices and successful HCT of YLHIV. We used a stepwise approach to the multilevel model building [24]. Model 1 included a fixed and random intercept to assess if successful HCT significantly varied across clinics. We also computed intraclass correlations to warrant examining differences between clinics in HCT success using the following formula:

$$ICC = \frac{\tau_{00}}{\tau_{00} + 3.29}$$

where τ_{00} equals the log odds of YLHIV having a successful HCT. Model 2 added YLHIV-specific individual-level fixed effects to examine the relationship between individual-level factors and successful HCT. To assess the extent to which individual- and clinic-level variables explained additional variation in successful HCT, Model 3 includes Model 2 plus adolescent clinic best practices, and Model 4 includes Model 2 plus adult clinic best practices. We assessed change in −2 log likelihood (−2LL) across models; the best model was classified as the model that explained the most difference from Model 1 in −2LL change.

Given the relatively small number of clinics (N = 13), we used Fisher's exact and chi-square tests to compare adolescent and adult clinic best practice strategies across clinics where 50% or more of youth had successful HCT to clinics and where less than 50% of youth had successful HCT. We used the 50% cut-off, as it is higher than existing chronic disease HCT rates [25] and captures a meaningful target for care continuity for HIV-related HCT.

All analyses were conducted in SPSS version 24.0 (Armonk, NY) and SAS version 9.4 (Cary, NC). Statistical significance was defined as $p < .1$ to detect any potentially relevant effects despite a small clinical sample size.

Qualitative analyses

We examined staff's HCT-related recommendations using the constant comparative method [26], [27]. Two researchers independently conducted line-by-line coding on each transcript to create a codebook. This codebook was then summarized and refined into a coding matrix, which also incorporated themes from existing literature [28]. Two researchers applied the finalized codes to all transcripts using Atlas.ti 7.5 (Atlas.ti, Berlin, Germany), with greater than 90% inter-rater agreement. Coding disagreements were resolved through research team consensus.

Results

Individual and clinic characteristics

Table 1 highlights youth and clinic characteristics. A total of 132 youth were included in final analyses (three were excluded because of missing data on key variables). The majority of youth were age 24 (n = 104, 78.8%), male (n = 100, 75.7%), black (n = 103, 78.0%), identified as a sexual minority (n = 83, 62.9%), had attended an HIV-related care appointment in the past 3 months (n = 119, 90.2%), had Medicaid (n = 86, 65.2%), reported ≥95% adherence to their antiretroviral therapy medication (n = 87, 65.9%), and were virally suppressed (n = 92, 69.7%). Fewer youth identified as Hispanic (n = 24, 18.2%) or reported being distressed (n = 15, 11.4%). On average, youth reported moderate disclosure-related stigma scores (M = 1.81 out of 4, SD = .82).

Table 1. Individual- and clinic-level characteristics of 132 young people with HIV

YLHIV (N = 132)	**n**	**%**
Age (range 21–24) (y)		
24	104	78.8
Less than 24	28	21.2
Current gender		
Male	100	75.7
Female or transgender	32	24.2
Race		
Black	103	78.0
White	9	6.8
Other	20	15.2
Hispanic		
Yes	24	81.8
No	108	18.2
Sexual orientation		
Straight	28	21.2
Gay/lesbian	83	62.9
Bisexual	18	13.6
Questioning	3	2.3
Insurance		
Private	31	23.5
Medicaid	86	65.2
No insurance	15	11.4
Attend HIV care in past 3 months		
Yes	119	90.2
No	13	9.9
Successful healthcare transition (at least one adult HIV appointment)		
Yes	49	37.1
No	84	63.6
ART adherence		
Always or almost always (≥95%)	87	65.9
Most of the time (75%–94%)	23	17.4
Less than 75% of the time (0%–74%)	22	16.7
Viral load (range ≤20–6,247,816)		
Not suppressed	38	28.8
Suppressed	92	69.7
Missing	2	1.5
	Mean	**SD**
Stigma Disclosure Scale (0 (low)–4 (high))	1.81	.82
	n	**%**
Youth perspective: Clinic staff described adolescent and adult clinic differences		
Yes	110	83.3
No	22	16.7
Youth perspective: Clinic staff supported adult clinic decision-making		
Yes	110	83.3
No	22	16.7
Youth perspective: Clinic staff discussed potential HCT challenges		
Yes	106	80.3
No	26	19.7
Brief Symptoms Inventory Scale: Distressed		
Yes	15	11.36
No	117	88.64
Site-specific clinic variables (N = 13)	**n**	**%**
Number of best practices (0–8) employed by adolescent clinics		
7–8 strategies	5	38.5
6 or fewer strategies	8	61.5
Number of best practices (0–4) employed by adult clinics		
4 strategies	4	30.8
3 or fewer strategies	9	69.2

ART = antiretroviral; SD = standard deviation; YLHIV = youth living with HIV.

Approximately 37% (n = 49) of YLHIV successfully transitioned to adult care. The majority of youth felt that adolescent clinics prepared them for HCT: 83.3% (n = 110) reported that adolescent clinic staff discussed potential HCT challenges and provided support in choosing where to receive adult care, and 80.3% (n = 106) stated that adolescent clinic staff discussed differences between adolescent and adult health systems.

Among the 13 adolescent clinics, five employed all best practice strategies, whereas four of the 20 receiving adult clinics employed all best practice strategies.

Mixed effects logistic regression models

Table 2 summarizes the mixed effects logistic regression model results. Model 1 (HCT assessment by site) indicated that successful HCT varied across adolescent clinic sites ($\tau 00 = .99$, $z(12) = 1.55$, $p = .06$), explaining about 23% of variability in the successful HCT rate. In Model 2, the addition of individual-level characteristics of YLHIV improved the model fit by a 22.2 difference ($\tau 00 = 1.56$, $z(12) = 1.51$, $p = .07$). There was a negative relationship between disclosure-related stigma and successful HCT ($b = -.79$, $p = .03$); as youth's disclosure-related stigma increased, the predicted odds of successful HCT decreased. There were no other significant relationships.

In Model 3—which added adolescent clinic best practices—using seven or eight best practices was associated with successful HCT, improving model fit by a 3.73 difference from Model 2 and 29.93 from Model 1 ($\tau 00 = 1.02$, $z(11) = 1.38$, $p = .08$). YLHIV who attended adolescent clinics that used seven or eight best practice strategies were 4.84 times more likely to have a successful HCT ($b = -1.58$, $p = .04$) compared with clinics with six or fewer strategies. Perceived disclosure-related stigma remained negatively associated with successful HCT ($b = -.83$, $p = .02$). Youth without health insurance were 6.74 times more likely to have a successful HCT ($b = 1.91$, $p = .04$). In Model 4—which added adult clinic best practices—having all four best practices was not associated with successful HCT ($b = .59$, $p = .57$).

Based on changes in −2LL from Model 1 (unconditional model) to models accounting for individual- and clinic-level factors, Model 3 ($\chi 2(1) = 25.93$, $p = .06$) appeared to be the better fitting model than Models 2 ($\chi 2(1) = 22.20$, $p = .07$) and 4 ($\chi 2(1) = 22.51$, $p = .06$).

Fisher’s Exact and Chi-square tests

The majority of adolescent clinics (n = 12, 92.3%) reported having an HCT protocol and an HCT staff person, providing youth with information and support related to options for adult care, and discussing insurance protocols with YLHIV. The majority also had a clinic staff member attend the first appointment with youth (n = 9, 69.2%) and had multiple adult clinic options (n = 7, 53.8%). Relatively few adolescent clinics had an adult provider come to the adolescent clinic to treat or meet youth before HCT (n = 4, 30.8%) or shared clinical space with adult clinic(s) (n = 3, 23.1%). There were no significant differences between these individual clinical variables and sites that transferred more than 50% of youth to adult care (see Table 3).

Table 2. Individual- and clinic-level factors associated with successful healthcare transition (N = 132)

	Model 1	Model 2		Model 3		Model 4	
	b	b	OR (95% CI)	b	AOR (95% CI)	b	AOR (95% CI)
Individual level							
Intercept	−.69	−3.58		−4.37[a]		−3.39	
Age 24 (<24 referent)		1.07	2.91 (.78–10.97)	1.05	2.84 (.78–10.41)	1.02	2.76 (.73–10.44)
Male (no referent)		.17	1.18 (.37–3.75)	.25	1.29 (.41–4.05)	.18	1.19 (.38–3.77)
Hispanic (no referent)		.45	1.56 (.45–5.37)	.45	1.58 (.46–5.46)	.42	1.52 (.44–5.22)
Insurance (private referent)							
Medicaid		.41	1.51 (.45–5.03)	.54	1.71 (.52–5.69)	.45	1.56 (.47–5.22)
No Insurance		1.59	4.91 (.77–31.12)	1.91	6.74 (1.04–43.59)	1.57	4.79 (.77–29.91)
Attend HIV care in past 3 months (no referent)		1.21	3.34 (.50–22.46)	1.29	3.62 (.56–23.50)	1.21	3.37 (.50–22.65)
Stigma Disclosure Scale (0–4)		−.79[a]	.45 (.23–.91)	−.83[a]	.44 (.33–.87)	−.82[a]	.44 (.22–.89)
Youth perspective: Differences between Clinics (no referent)		.53	1.70 (.31–9.44)	.60	1.82 (.33–10.17)	.50	1.66 (.30–9.22)
Youth perspective: Support with adult clinic (no referent)		1.16	3.18 (.46–22.07)	.98	2.67 (.40–17.82)	1.22	3.40 (.49–23.87)
Youth perspective: Discussed challenges (no referent)		.38	1.46 (.29–7.48)	.44	1.56 (.30–7.90)	.40	1.49 (.29–7.69)
Distressed (no referent)		−1.04	.36 (.07–1.87)	−.95	.39 (.08–1.98)	−1.10	.33 (.06–1.78)
Clinic level							
Intercept	.99	1.56	.06	1.03		1.52	
Best practices: Adolescent clinic (≤7 referent)				1.58[a]	4.84 (1.00–23.33)		
Best practices: Adult clinic (≤3 referent)						−054	.59 (.09–3.86)
Model fit							
−2LL	161.49	139.29		135.56		138.98	

−2LL = −2 log likelihood AOR = adjusted odds ratio; CI = confidence interval.

Table 3. Best practices for adolescent clinic by percentage of youth who had a successful healthcare transition (N = 13)

	Percent transitioned		Total	*p* Value
	< 50%	≥ 50%		
Have formal (or informal) transition protocol				.769
No	1 (10.0)	0 (0)	1 (7.7)	
Yes	9 (90.0)	3 (100.0)	12 (92.3)	
Have a specific "transition" staff person (e.g., social worker, case manager) at adult clinic				.231
No	0 (0)	1 (33.3)	1 (7.7)	
Yes	10 (100.0)	2 (66.7)	12 (92.3)	
Have adult provider go to adolescent clinic to treat or meet youth just before transition				.706
No	7 (70.0)	2 (66.7)	9 (69.2)	
Yes	3 (30.0)	1 (33.3)	4 (30.8)	
Have adolescent clinic staff attend first adult clinic appointment with youth				.706
No	3 (30.0)	1 (33.3)	4 (30.8)	

	Percent transitioned		Total	*p* Value
	< 50%	≥ 50%		
Yes	7 (70.0)	2 (66.7)	9 (69.2)	
Provide information and support related to options for where to receive adult care				.769
No	1 (10.0)	0 (0)	1 (7.7)	
Yes	9 (90.0)	3 (100.0)	12 (92.3)	
Insurance protocols (e.g., making insurance claims, carrying insurance card)				.769
No	1 (10.0)	0 (0)	1 (7.7)	
Yes	9 (90.0)	3 (100.0)	12 (92.3)	
Adolescent clinic site classification				.420
Same clinical space	3 (30.0)	0 (0)	3 (23.1)	
Same medical system	3 (30.0)	2 (66.7)	5 (38.5)	
Different medical system	4 (40.0)	1 (33.3)	5 (38.5)	
Number of adult transition clinic(s)				.563
Adolescent clinic primarily transitions to 1 adult clinic	5 (50.0)	1 (33.3)	6 (46.2)	
Adolescent clinic primarily transitions to multiple adult clinics	5 (50.0)	2 (66.7)	7 (53.8)	
Best Practices: adolescent clinic (7–8 strategies)				
No	7 (70.0)	1 (33.3)	8 (61.5)	.315
Yes	3 (30.0)	2 (66.7)	5 (38.5)	

Table 4. Best practices for adult clinic by percentage of youth who had a successful healthcare transition (N = 13)

	Percent transitioned		Total	*p*-Value
	<50%	≥ 50%		
Have formal (or informal) transition protocol				.769
No	1 (10.0)	0 (0)	1 (7.7)	
Yes	9 (90.0)	3 (100)	12 (92.3)	
Have a specific "transition" staff person (e.g., social worker, case manager) at adult clinic				.203
No	2 (20.0)	2 (66.7)	4 (30.8)	
Yes	8 (80.0)	1 (33.3)	9 (69.2)	
Have adult provider go to adolescent clinic to treat or meet youth just before transition				.510
No	7 (70.0)	1 (33.3)	6 (61.5)	
Yes	3 (33.3)	2 (50.0)	7 (38.5)	
Have adolescent clinic staff attend first adult clinic appointment with youth				.685
No	6 (60.0)	2 (66.7)	7 (53.8)	
Yes	4 (40.0)	1 (33.3)	6 (38.5)	
Best practices: Adult clinic (4 strategies)				.706
No	7 (70.0)	2 (66.7)	9 (69.2)	
Yes	3 (30.0)	1 (33.3)	4 (30.8)	

Table 5. HCT recommendations from adolescent and adult clinic staff

Recommendation	Adolescent clinic staff	Adult clinic staff
Youth specific		
Develop basic life skills for medical and health management	That was a change we made. I like the change we've added the transition groups on for <inaudible>[00:51:05] so that they can even build up that peer support as well. And then I like the fact that we have now added the financial components and just the life _____ [00:51:15] skills. The skills that every young adult should have, that they need to have, we've added that to our support groups now too. (Site W Clinic 1 (W1)-Adolescent Social Worker)	You know, if there's a life skills group somewhere in the process, whether it's on the adult side or the youth side, if there was a life skills group that they can join into so they can learn about that insurance, learn about budgeting or get the housing referrals before they even get deep into the clinic, I think that that would help as well. (Site X Clinic c1 (Xc1)-Adult Social Worker)
Provide patient-centered care where expertise and experiences of YLHIV are acknowledged and valued in the HCT process	We've learned to listen to them a lot more, let them guide how we start out transition process more so than us just deciding this is what needs to be done, this is what you should do, and this is how you do it. Because, of course, most youth have to have a buy-in. With most youth, it's kinda like even with little kids. They gotta think, "It's my idea." So an adult just telling me, "This is what you gotta do. Do this. Do this, do this." They tend to pull back a little bit or just don't wanna do it because you're telling them. But, if you can get them to feel like, "This is something I need to do. This is something I should wanna do. This is my idea. I'm determining how my care goes and my path," it tends to be a lot easier, a lot more smoother. (W1-Adolescent Social Worker)	I think part of it's going to come with— is coming with time and with education that we get from the patients. So patients give you the lead on how they need to be cared for and what their needs are. But I think more and more with time that our adult staff are learning what the youth need and how to take care of them better. I'm trying to think of what else. I don't know. I can't think of any other answers right now. (Wc1-Adult Nurse Practitioner)
Clinic specific		
Develop and implement a formalized HCT protocol	…A structured protocol around transitioning, not just the, "Oh, well, you're about to turn 25 or 21, whichever year you transition, so let's figure out where you're going to go." It's really thinking about it early and taking the steps to make sure that the young person doesn't feel rushed in the process. (N2-Adolescent Social Worker)	…The physicians themselves sort-of being more involved in the transition process…I mean, if money weren't an object, perhaps having one staff person, a social worker or someone specifically devoted to the youth. So sort-of have a transition within the transition where they transition to here…You'd have to have a physician who specifically wants to work with that population, the age group between just coming over from adolescent care to adult care. (Ra2-Adult Social Worker)
Provide staff training on developmental stage and context of YLHIV to provide competent care	I guess learning, training on how to be more…youth-friendly because they're adults, they're 25, but they're not 40 or 50 and really responsible like a 40- or 50-year-old…Just some kind of training on how to meet the young adult where they are and not expect them to be at a different level when they're not. (K1-Adolescent Social Worker)	…An awareness that these kids, even though they're adults, they either may not be cognitively adults or that they are stunted…Or they're just going to have a hard time, bottom line, because of what's going on, as a normal young person trying to navigate life…And I think that there needs to be a little bit of flexibility… Just understanding that this is a true, special, and key population and having the flexibility to say,

Recommendation	Adolescent clinic staff	Adult clinic staff
		"Well, because they are having a hard time, let's try to be a little bit kinder, gentler in our approach." (Xb1- Adult Physician)
Ensure patient and peer navigation are available at the clinic to support HCT for YLHIV	I think that having youth find kind-of a representative or buddy in the clinic is key. Someone…that the youth is actually comfortable or has a good attachment to…Maybe the first person that they met. I think that that's something key to gain trust in the clinic and in the clinic setting. (T2-Adolescent Physician)	I think that if your navigator is in his 60s, that's not—We have discussed having a younger youth navigator, peer navigators on site. So that's potentially something that we could do to make it more youth-friendly. (Wa1-Adult Physician)
Provide comprehensive care services to support all healthcare needs of YHIV	I think that it would be nice to have a lot more transition services. I know that we continue to offer…mental health services for six months after someone transitions…The one I'm thinking of [is] pharmacy support. Childcare. I think that there's just some additional services that would make it helpful. (Z3-Mental Health and Substance Abuse Counselor)	…A lot of mental health services, even psychological services on site and social work on site. So I think those support services are critical because often, when the patients come in, if they have an issue, that can be the only time that we have to work with them sometimes, so to say, "Could you please come back tomorrow because I know my social worker will be here?" When they walk out the door, we've lost them for a while. And without having been able to help them. (Ia1-Adult Physician)
Prioritize interclinic collaboration and data sharing to support HCT	…Establishing a relationship with an adult case manager who is very hands-on early on. So someone who is youth-focused and who's willing to provide a little bit more intensive services…someone who's willing to follow up with the youth in the community, engage with them, with us, with the new provider, that's a big piece, and also having an adult provider who's collaborative…Really, what it comes down to is collaboration with the adult providers and being a little bit more flexible and youth-oriented, especially during the initial transition. (Q2-Adolesent Social Worker)	The other is similar data sharing that would be from one clinical entity to another. So, say [a youth] comes to me for care and then goes to [another clinic] for six months because they're closer…[The youth] appear like they're out of care, but they're actually in care. I don't know about that. And so those kinds of information sharing networks are critical at the network level…the systems level, to be able to then be in touch with who's out and who needs to be contacted and brought back in. (Xa1-Adult Physician)

HCT = healthcare transition.

Similarly, the majority of adult clinics had an HCT protocol (n = 12, 92.3%) and an HCT staff person (n = 8, 69%). Fewer adult clinics reported that adult providers treated or met youth in the adolescent clinic before transition (n = 7, 38.5%) or that an adolescent staff person was present at the first adult appointment of YLHIV (n = 6, 38.5%). There were no significant differences between these individual clinical variables and the sites that transferred more than 50% of youth to adult care (see Table 4).

Healthcare transition-related recommendations

The adolescent and adult clinic providers focused the majority of their HCT recommendations and strategies at the clinic level (summarized in Table 5). These recommendations included staff training around adolescent development, creating formal HCT protocols, strengthening communication and data sharing between the adolescent and adult clinics, and offering more comprehensive HCT-related care services to support YLHIV. The few youth-specific recommendations centered on providing support and skill development for youth to manage their own healthcare (e.g., life skills and being assertive in the healthcare environment) and allowing youth to guide their own individualized HCT plan (e.g., listening to their unique needs).

Discussion

This prospective study across 14 ATN clinical sites highlights the complex set of individual- and clinic-level factors associated with HCT. Although being "transition eligible" was an inclusion criterion, the majority of YLHIV (63%) did not successfully transition. The youth who did not transition may have been unsuccessful for a variety of reasons. Some likely never left the adolescent clinic; in qualitative interviews, some providers reported keeping youth past the age of 24; others may have returned to care in the adolescent clinic despite being "ready" for transfer, and additional YLHIV were lost to care. This rate of successful transition—37%—is low, particularly given the importance of maintaining viral suppression for individual and public health [29]. This lower rate may be due to our follow-up occurring at 9 months as opposed to 1 year. It might also be that ATN clinical sites are particularly well-resourced, "one stop shops," which make it difficult for YLHIV to leave a clinical space that provides wrap-around and social services such as mental health, housing, and job training. More work is needed to comprehensively understand both the operationalization of transition "readiness" and the longer term HCT trajectory given the low rates of HCT and the high level of disengagement after 1 year [18], [19].

At the individual-level, disclosure-related stigma was associated with HCT. Youth who reported higher levels of HIV disclosure-related stigma (i.e., were more fearful of telling people they had HIV) were less likely to have successful HCT. Receiving care at a new clinic requires youth to repeatedly disclose to new individuals (e.g., receptionist, nurse, doctor, and social worker), a process that often involves sharing traumatic experiences. This forced retelling is necessary for a successful HCT, but for YLHIV who particularly fear disclosure, it may serve as a barrier to care engagement in a new clinic [30]. Research highlights the importance of a positive experience with first disclosure [31], suggesting a critical role for adult clinics in supporting YLHIV (especially those with fears around disclosure) during HCT. Further, adolescent HIV clinics are often situated within general adolescent clinics, so youth can attend without friends or family

knowing why. In contrast, many adult HIV clinics are HIV-only, which may increase the chance that family, friends, and/or other community members of YLHIV might learn about their status through unintentional disclosure [2].

Not having health insurance at baseline was positively associated with successful HCT. This finding, although unexpected, may have occurred for the following reasons. First, of the 16 youth who lacked insurance at baseline, 50% reported having insurance at follow-up, which suggests that they were able to receive insurance through the adult clinic. Of the remaining eight youth who lacked insurance at baseline, 31.3% (n = 5) were lost to follow-up and 18.8% (n = 3) remained uninsured. Second, clinics who cover youth through Ryan White may be forced to transfer YLHIV before age 25, whereas those with private insurance have fewer restrictions. Lastly, perhaps because YLHIV without insurance are deemed particularly vulnerable, adolescent clinic staff may have engaged in additional measures (e.g., going with the youth to the first adult clinic appointment or, when possible, finding a clinic within the same medical system) to help facilitate their HCT. Future work should examine the role of insurance (e.g., parental insurance and disclosure) on HCT trajectories.

Clinic-level factors also influenced HCT success. Specifically, adolescent clinics that employed seven or eight best practices were almost five times more likely to have more than 50% of their YLHIV successfully transition to adult care. Individual practices were not significantly associated with HCT, highlighting the importance of "bundled services" to support YLHIV. This finding builds on previous research focused on YLHIV care linkage and engagement [32]—since HCT requires that youth re-link and re-engage. It further indicates that providers' qualitative recommendations focused on clinical-level factors such as data sharing, clinics' patient population, and the type of provider that completes the linkage/engagement are relevant to care continuity of YLHIV [32] and underscore the importance of engaging in concrete structural change within a clinic to ensure that processes exist to facilitate successful HCT of YLHIV.

HIV-related HCT is a complicated process especially within the different pediatric/adolescent and adult medicine subcultures [4]. The qualitative data identified useful HCT recommendations to support YLHIV that acknowledged the need of incorporating a developmental perspective within the compounding challenges of also living with HIV. Accordingly, the majority of recommendations focused on changes for adolescent clinics (e.g., less handholding, improved data sharing, and refinement of streamlined HCT processes) and/or adult clinics (e.g., staff training on adolescent development and more flexibility) to better support HCT. Many of these changes can be implemented across multiple clinic settings–some quickly and easily (e.g., provide basic life skills education). In contrast, some of the proposed structural changes (e.g., shared medical records) may be more laborious but could also dramatically improve care engagement and health outcomes for YLHIV [16], [30].

Strengths and limitations

Several study limitations should be considered. First, the participating ATN sites are in urban areas with relatively high HIV prevalence among adolescents. HCT may be affected by different issues in cities or in rural areas with lower HIV prevalence [33]. Second, the follow-up period was limited to 9 months, so it is possible that some of the YLHIV may have had a successful

HCT within a year—or even longer. Thus, future work should extend follow-up periods to examine HCT trajectories, especially as the operationalization of HCT success is complicated and we measured only one (essential) component of HCT—"transfer" or adult care linkage [14], [16], [30]. Initial linkage does not ensure long-term engagement [8]: only about 50% of youth who transferred were retained in adult care after 1 year [18], [19]. Finally, although this geographically diverse study included 13 distinct clinical sites that supported HCT for YLHIV, this sample size is small for the purposes of multilevel modeling, which resulted in reduced power for examining the influence of clinical best practices. This suggests that our clinic-level findings (from well-resourced and HCT supportive clinics) are particularly conservative and that the actual effect size of employing seven or eight adolescent clinic best practices is likely much larger.

This is the first study to prospectively examine HIV-related HCT from the perspective of YLHIV, as well as clinic staff and providers from adolescent and adult clinics. Results suggest that involvement from both the adolescent and adult clinics is critical to provide coordinated care, thus highlighting the importance of cultivating interclinic connections to support YLHIV during HCT [4]. The data allow for the identification of possible intervention leverage points to support HCT; future research needs to examine long-term HCT trajectories to develop interventions that both YLHIV and providers at adolescent and adult clinics can use to facilitate successful HCT. Addressing the multiple factors affecting HCT is essential for ensuring continuous care engagement for YLHIV.

Funding Sources

This work was supported by The Adolescent Trials Network for HIV/AIDS Interventions (A.E. Tanner, Protocol Chair) from the National Institutes of Health(U01 HD 040533 and U01 HD 040474) through the National Institute of Child Health and Human Development (B. Kapogiannis), with supplemental funding from the National Institutes on Drug Abuse (NIDA) (S. Kahana) and Mental Health (P. Brouwers, S. Allison). Morgan Philbin was supported by a NIDA-funded K01 (K01DA039804A).

Acknowledgments

The ATN's Community Prevention Leadership Group scientifically reviewed the study protocol. Network, scientific, and logistical support was provided by the ATN Coordinating Center (C. Wilson, C. Partlow) at The University of Alabama at Birmingham. The ATN Data and Operations Center at Westat, Inc. (D. Monte) provided network operations and analytic support. Dr. Kelly Rulison (UNCG's Department of Public Health Education) and Dr. Jeffrey D. Labban (UNCG's School of Health and Human Science Office of Research) provided essential statistical consultation.

The authors acknowledge the contribution of the investigators and staff at the following sites who participated in this study: University of South Florida, Tampa (Emmanuel, Straub, Enriquez-Bruce); Children's Hospital of Los Angeles (Belzer, Tucker); Children's National Medical Center (D'Angelo, Trexler); Children's Hospital of Philadelphia (Douglas, Tanney); John H. Stroger Jr. Hospital of Cook County and the Ruth M. Rothstein CORE Center

(Martinez, Henry-Reid, Bojan); Montefiore Medical Center (Futterman, Campos); Tulane University Health Sciences Center (Abdalian, Kozina); University of Miami School of Medicine (Friedman, Maturo); St. Jude's Children's Research Hospital (Flynn, Dillard); Baylor College of Medicine, Texas Children's Hospital (Paul, Head); Wayne State University (Secord, Outlaw, Cromer); Johns Hopkins University School of Medicine (Agwu, Sanders, Anderson); The Fenway Institute (Mayer, Dormitzer); and University of Colorado (Reirden, Chambers). The investigators are grateful to the members of the local youth Community Advisory Boards for their insight and counsel and are indebted to the youth who participated in this study.

References

[1] Blum RW, Garell D, Hodgman CH, et al. Transition for child-centered to adult health care systems for adolescents with chronic conditions: A position paper of the Society of Adolescent Medicine. J Adolesc Health 1993;14:570–6.

[2] Tanner AE, Philbin MM, Duval A, et al. “Youth friendly” clinics: Considerations for linking and engaging HIV-infected adolescents into care. AIDS Care 2014;26:199–205.

[3] Peter N, Forke C, Ginsburg K, Schwarz D. Transition from pediatric to adult care: Internists’ perspectives. Pediatrics 2009;123:417–23.

[4] Tanner AE, Philbin MM, Ma A, et al. Adolescent to adult HIV healthcare transition from the perspective of adult providers across 14 cities in the United States. J Adolesc Health 2017;61:434–9.

[5] Szalda DE, Jimenez ME, Long JE, et al. Healthcare system supports for young adult patients with pediatric onset chronic conditions: A qualitative study. J Pediatr Nurs 2015;30:126–32.

[6] Schultz AT, Smaldone A. Components of interventions that improve transitions to adult care for adolescents with Type 1 diabetes. J Adolesc Health 2017;60:133–46.

[7] Szalda DE, Piece L, Brumley L, et al. Associates of engagement in adult-oriented follow-up care for childhood cancer survivors. J Adolesc Health 2017;60:147–53.

[8] Hussen SA, Chahroudi A, Boylan A, et al. Transition of youth living with HIV from pediatric to adult-oriented healthcare: A review of the literature. Future Virol 2014;9:921–9.

[9] Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: A systematic review. Arch Dis Child 2011;96:548–53.

[10] Office of National AIDS Policy. National HIV/AIDS Strategy for the United States: Updated to 2020. 2015.

[11] Kakkar F, Van der Linden D, Valois S, et al. Health outcomes and the transition experience of HIV-infected adolescents after transfer to adult care in Québec, Canada. BMC Pediatr 2016;16:109.

[12] Fish R, Judd A, Jungmann E, et al. Mortality in perinatally HIV-infected young people in England following transition to adult care: An HIV Young Persons Network (HYPNet) audit: Mortality in young adults with perinatal HIV. HIV Med 2014;15:239–44.

[13] Philbin MM, Tanner AE, Duval A, et al. Linking HIV-positive adolescents to care in 15 different clinics across the United States: Creating solutions to address structural barriers for linkage to care. AIDS Care 2014;26:12–9.

[14] Philbin MM, Tanner AE, Chambers BD, et al. Transitioning HIV-infected adolescents to adult care at 14 clinics across the United States: Using adolescent and adult providers' insights to create multi-level solutions to address transition barriers. AIDS Care 2017;29:1227–34.

[15] Tepper V, Zaner S, Ryscavage P. HIV healthcare transition outcomes among youth in North America and Europe: A review. J Int AIDS Soc 2017;20:21490.

[16] Straub DM, Tanner AE. Health care transition from adolescent to adult services for HIV-infected youth. Lancet Child Adolesc Health 2017.

[17] Cervia JS. Easing the transition of HIV-infected adolescents to adult care. AIDS Patient Care STDS 2013;27:692–6.

[18] Ryscavage P, Macharia T, Patel D, et al. Linkage to and retention in care following healthcare transition from pediatric to adult HIV care. AIDS Care 2016;28:561–5.

[19] Hussen SA, Chakraborty R, Knezevic A, et al. Transitioning young adults from paediatric to adult care and the HIV care continuum in Atlanta, Georgia, USA: A retrospective cohort study. J Int AIDS Soc 2017;20:21848.

[20] Tanner AE, Philbin MM, DuVal A, et al. Transitioning HIV-positive adolescents to adult care: Lessons learned from twelve adolescent medicine clinics. J Pediatr Nurs 2016;31:537–43.

[21] Simoni JM, Kurth AE, Pearson CR, et al. Self-report measures of antiretroviral therapy adherence: A review with recommendations for HIV research and clinical management. AIDS Behav 2006;10:227–45.

[22] National Diabetes Education Program. Pediatric to Adult Diabetes Care Transition Planning Checklist. (2014).

[23] American Academy of Pediatrics. Transitioning HIV-infected youth into adult health care. Pediatrics 2013;132:192–7.

[24] Dickinson LM, Basu A. Multilevel modeling and practice-based research. Ann Fam Med 2005;3:S52–60.

[25] Oswald DP, Gilles DL, Cannady MS, et al. Youth with special health care needs: Transition to adult health care services. Matern Child Health J 2013;17:1744–52.

[26] Buetow S. Thematic analysis and its reconceptualization as “saliency analysis”. J Health Serv Res Policy 2010;15:123–5.

[27] Glaser BG, Strauss AL. The discovery of grounded theory: Strategies for qualitative research. Aldine Pub. Co.; 1967.

[28] MacQueen K, McLellan E, Kay K. Codebook development for team-based qualitative analysis. Cult Anthropol Methods 1998;10:31–6.

[29] Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. N Engl J Med 2011;365:493–505.

[30] Tanner AE, Philbin MM, DuVal A, et al. Transitioning HIV-positive adolescents to adult care: Lessons learned from twelve adolescent medicine clinics. J Pediatr Nurs 2016;31:537–43. doi:10.1016/j.pedn.2016.04.002.

[31] Chaudoir SR, Quinn DM. Revealing concealable stigmatized identities: The impact of disclosure motivations and positive first disclosure experiences on fear of disclosure and well-being. J Soc Issues 2010;66:570–84.

[32] Philbin MM, Tanner AE, DuVal A, et al. Factors affecting linkage to care and engagement in care for newly diagnosed HIV-positive adolescents within fifteen adolescent medicine clinics in the United States. AIDS Behav 2014;18:1501–10.

[33] Straub DM, Deeds BG, Willard N, et al. Partnership selection and formation: A case study of developing adolescent health community-researcher partnerships in fifteen US communities. J Adolesc Health 2007;40:489–98.